



NATIONAL PSORIASIS FOUNDATION OVERVIEW OF FEDERAL ADVOCACY INITIATIVES

Goal: Boost psoriasis research for a CURE and improve access to treatments

Authorizing Legislation

An authorizing bill provides the authority for a federal program or agency to exist. The bill details what the specific program or agency's policy and activities should be for a specified period of time. Members of Congress show formal support for an authorizing bill by becoming co-sponsors—adding their names to an official list of supporters. The greater the number of co-sponsors on a bill, the greater the likelihood that it will be moved through the legislative process. An authorizing bill does not become law unless an identical version of it is passed by the House and by the Senate, and signed by the President.

The National Psoriasis Foundation worked with Representative David Wu (D-Ore.-1) and Senator Robert Menendez (D-N.J.) on the introduction of an authorizing bill—the Psoriasis and Psoriatic Arthritis Research, Cure, and Care Act (PPARCCA) of 2007 (H.R. 1188/S. 1459)—the first-ever comprehensive psoriasis legislation. The National Psoriasis Foundation will, through online action alerts and meetings during Capitol Hill Day, request that members of Congress show their support for the bill by becoming co-sponsors. If passed by the House and Senate, the bill would be sent to the President to be signed into law.

Report Language

When a Congressional committee submits a bill to the full Senate or House, the committee typically publishes a report explaining the bill. One such bill is an “appropriations” bill, which outlines funding for the agencies and programs that have a role in psoriasis and psoriatic arthritis research. This bill comes out of the Labor-Health and Human Services-Education (LHHS) committee. The accompanying report details the committee's recommendations for how the money should be spent. This text is referred to as “report language” and serves as guidance to the federal agencies funded under the bill.

Advocacy organizations such as the National Psoriasis Foundation draft report language that affects the agencies and programs they seek to influence. Then we ask members of Congress to submit the language to the relevant Senate and House appropriations subcommittees. The directives contained in appropriations reports do not have the force of law; however, they strongly encourage departments or agencies to take specified action.

Each year the National Psoriasis Foundation drafts report language for inclusion in both the House and Senate LHHS appropriations bills to urge federal agencies to increase their psoriasis research activities and undertake particular steps to advance toward a cure and improve access to care.

Resolutions

House or Senate resolutions are nonbinding forms of legislation that are used by members of Congress to elevate awareness about an issue and/or express a point of view of Congress. Resolutions do not require presidential approval. Resolutions are a good tool for organizations to use when building awareness around a specific cause and/or to help energize grassroots involvement and support.

In the past, the National Psoriasis Foundation has had two resolutions introduced and passed in Congress: (1) to recognize Psoriasis Awareness Month (2005) and (2) to urge development of better psoriasis treatments and a cure, and to improve access to care (2006).

“Dear Colleague” Letters

A “Dear Colleague Letter” is correspondence sent by one or more members of Congress to other members of Congress to solicit support (e.g. to co-sponsor a bill). Ideally, to secure the support needed and enhance the influence of the letter, it is best to have the letter initiated by a Democrat and a Republican.

Other Congressional Actions/Activities

Congressional Record Statements—The National Psoriasis Foundation has worked with members of Congress to have statements about psoriasis and psoriatic arthritis inserted into the Congressional Record (the official daily record of all the activities of the House and the Senate). Congressional Record Statements help elevate awareness of issues among other members of Congress and help to validate the importance of particular matters before the Congress.

Letters to Federal Agencies—Members of Congress regularly send correspondence to federal agencies to inquire about the status of a particular matter, urge a particular action, solicit information for a constituent, etc. The National Psoriasis Foundation has worked with members of Congress to send letters to a number of agencies including the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention. The responses from the agencies have helped to inform the National Psoriasis Foundation’s advocacy activities (e.g. the development of a “white paper” outlining the areas in which the NIH should be investing to advance the research that will lead to a cure).

Meetings with Federal Agencies

Federal agencies such as the National Institutes of Health (NIH) implement programs and take action in response to congressional directives, requests and mandates. Many federal agencies have programs that directly or indirectly relate to psoriasis and psoriatic arthritis. Meeting with federal agencies is an ongoing process and should be carried out in concert with activities that involve lobbying on Capitol Hill. For certain initiatives, it is important to have support from federal agencies before you present the ideas to members of Congress and congressional staff.

National Psoriasis Foundation representatives meet with staff at various institutes and centers at the NIH on a regular basis. In addition, the Foundation has reached out to the Centers for Disease Control and Prevention to expand its collection of psoriasis and psoriatic arthritis data. These meetings have led to discoveries about programs and grants that may benefit the psoriasis community.

Another key role the National Psoriasis Foundation is playing this year is to co-chair the NIAMS Coalition—a coalition of some 60 health advocacy organizations whose disease areas are related to the mission of NIAMS—the National Institute of Arthritis and Musculoskeletal and Skin Diseases. The coalition lobbies for more research funding for NIAMS as a whole.